

**DIAGNOSTIC ACCURACY OF A CLASSIFICATORY ALGORITHM
FOR SELF INJURIOUS BEHAVIOURS AMONG CHILDREN AND
ADOLESCENTS WITH ATYPICAL DEVELOPMENT.**

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Dissertation submitted to
The Tamil Nadu Dr.M.G.R. Medical University in part fulfillment of the requirement
of M.D. branch XVIII – Psychiatry final examination March -2008

DECLARATION

I hereby declare that this dissertation titled “**Diagnostic accuracy of a classificatory algorithm for self injurious behaviors among children and adolescents with atypical development.**” is a bonafide work done by me under the guidance of **Dr. Paul S.S. Russell**, Professor of psychiatry, Christian Medical College, Vellore. This work has not been submitted to any university in part or full.

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DECLARATION

I hereby declare that the investigations, which form the subject matter of this thesis, **“Diagnostic accuracy of a classificatory algorithm for self injurious behaviors among children and adolescents with atypical development.”** were carried out by **Dr. Satya Raj**, a bonafide trainee in psychiatry, under my guidance. This has not been submitted to any university in part or in full.

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ACKNOWLEDGEMENTS

I acknowledge my gratitude to Dr. Paul S.S. Russell, Professor of psychiatry, and my guide for being a constant source of help, support and encouragement and for making me take up this fascinating topic and guiding me in every step in the process.

I thank Dr.K.S.Jacob and Dr.Prathap Tharyan, Professors of Psychiatry for being an incessant source of encouragement. I am thankful to Dr. Priya and Dr Kannan for assisting me in my study.

I thank Ms. Sushila Russell, psychologist, for her kind guidance and inspiring words in the difficult times. I value the help of Mr. Simpson, Ms.Bhagya , Mrs. Mumtaz, Ms. Anna Daniel, Ms. Evangeline, Ms.Julie , Ms.Queen Mary, Ms. Meera Bai and other staff members of Nambikkai Nilayam, for the smooth progress of the study.

I like to express my gratitude to all the children who participated in this study and to their parents for having cooperated with me. I thank the research committee of Christian Medical College, Vellore for approval of funding of this project. I appreciate all my consultants and colleagues who rendered their co-operation during the study period. I am obliged to my parents, husband and friends who facilitated me to endure the challenge. Last but not the least my heart felt thanks to my kids who make everything worth while.

Dr.Satya Raj

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Introduction

CHAPTER I

INTRODUCTION

Issues of phenotypic heterogeneity of SIB are particularly critical to current efforts at mapping neurochemicals involved in causing self-injurious behaviours among children with atypical development.

Self Injurious Behaviour (SIB), defined as deliberate, non accidental, repetitive infliction of injuries resulting in tissue damage without suicidal intent is widely prevalent among children with atypical development. It results in significant morbidity resulting significantly compromised quality of life and mortality among this population with developmental disabilities (Symons et al, 1999). The management is resource intensive and therefore is major burden on the families (Silverstein 1987; King et al 1993), care-giving teams and countries' resources (National Institutes of Health, 1989; Emerson et al, 2004).

The neurobiology of SIB although is ill understood, and one of the most serious and difficult conditions to treat in child psychiatry, several potential treatments have been recognized. Among them the bio-psychosocial model of approach is holistic and clinically effective in preventing Self injurious behaviour (Mace and Mauk, 1995) and a diagnostic and management algorithm has been elaborated (Russell, 2006). The current study focuses on validating algorithm which would serve the purpose.

Review of Literature

CHAPTER II

REVIEW OF LITERATURE

1. DEFINITION

Self injurious behaviour (SIB) is defined as any self directed repetitive behaviour exhibited by a person that results in tissue damage (Tate and Baroff, 1966). Self injury is defined as the deliberate mutilation of the body or a body part, done not with the intent to commit suicide but as a way of managing emotions that seem too painful for words to express (Jacobs, 2000). Therefore, SIB is a behaviour that is self-directed and repetitive in nature that results in tissue damage but is not part of a suicidal attempt.

2. PREVALENCE

a) Normal population

SIB is seen in about 15% of the normal infants and toddlers. With increasing age the prevalence of SIB in this population decreases. SIB in infants aged 9-18 months is about 15%, 9% in the 2 yr olds and usually stops spontaneously by age 4 and does not require

any treatment unlike the SIB noted in children with atypical development (Romanczyk et al, 1982; Hammock et al, 1995).

b) Psychiatric disorders

Self injurious behaviour is present in approximately 4% of the general psychiatric population (Herpertz, 1995). SIB occurs in a wide variety of psychoses, neuropsychiatric disorders, borderline personality disorder, eating disorders, and psychoactive substance abuse where SIB appears to serve the purpose of reducing tension and regulating affect.

c) Developmental disabilities (atypical development)

The prevalence of self injurious behaviour in children with atypical development ranges from 2 to 19% in community samples (Maisto et al 1978, Schroeder et al, 1978; Griffin et al; 1980) and as high as 8% to 40% among the institutionalized population with developmental disabilities (Green et al 1967, Shodell et al 1978, Schroeder, 1980). In these individuals with developmental disabilities (like pervasive development disorders, stereotypic movement disorder, tic disorder and Lesch Nyhan syndrome) it may be related to neurochemical dysregulation (Robertson et al, 1989; Haw, et al 2001).

The prevalence of SIB among persons with intellectual disability is upto 11.4% (Hill & Bruininks, 1984). It is documented that lower the person's intellectual ability, the more frequent and more severe the self injurious behaviour is likely to be. Self injurious behaviour is found in 2.6% of the mildly, 3.4% of the moderately, 7.1% of the severely and 16.9% of the profoundly intellectually disabled persons (Jacobson, 1982). In these children with developmental disabilities the emergence of SIB is prior to the age of 5 years (Schneider et al, 1996, Murphy et al, 1999; Berkson et al, 2001; Hall et al, 2001).

3. GENETIC SYNDROMES AND SELF INJURIOUS BEHAVIOUR

Self injurious behaviour as a behavioural phenotype is documented in many genetically determined syndromes that also result in intellectual disabilities and atypical development of children (Deb, 1998) although the causal relationship between the genetic syndromes and the self injurious behaviour remains far from clear.

Several syndromes show predilection to certain body sites for self injury. In Lesch Nyhan, Prader-Willi, and Cornelia de Lange syndromes the extremities are the targeted sites for SIB but in syndromes like Smith-Magenis and Lowe syndromes SIB is widespread in topography (Symons & Thompson, 1997).

a) Lesch -Nyhan syndrome

First described in 1964 by Lesch and Nyhan, this rare X-linked recessive disorder is of purine metabolism error. It is caused by the complete or near absence of the enzyme hypoxanthine – guanine phosphoribosyl transferase. It occurs in 1:100,000 to 380,000 live births (Cauwels & Martens, 2005). Children affected with this disease are developmentally and physically delayed, and suffer from self injurious behaviour. Intractable self injurious behaviour in the form of severe lip and finger biting, gouging of eyes, face scratching, and head banging is noted (Cauwels & Martens, 2005) with the typical feature of partial or total destruction of perioral tissues (Jeong et al, 2006)

b) Prader-Willi syndrome

Prader-willi syndrome is not the result of deficit in seven genes although long arm of chromosome 15 is well known and all of which appear to be brain specific (Nicholls et al 1998; Nicholls, 1999). It is a multi system neurogenetic disorder characterized by infantile

hypotonic, mental retardation, short stature, hypogonadism, dysmorphic features, and hyperphagia with obesity. 97 % of children with this syndrome have an IQ below 70 (Butler, 1990). Self injurious behaviour in the form of skin picking, nail biting and rectal gouging is reported (Shapira et al, 2002). Behavioural phenotypic feature of skin picking is seen in upto 85% of the cases (Greenswag 1987; Clarke et al 1989; Cassidy 1992).

c) Cornelia De Lange syndrome

This is a genetic syndrome that results in developmental delay, intellectual disability and self injurious behaviour. Self injurious behaviour is seen characteristically affecting the fingers ,wrists and lower limbs (Berney et al, 1999). Small stature, microcephaly, limb abnormalities, facial features like upturned nose, micrognathia, thin lips ,high arched palate and long philtrum are seen.

d) Smith Magenis syndrome

This syndrome caused by an interstitial deletion involving the 17 p 11.2, is characterized by mental retardation, cognitive and behavioural profiles like being disobedient, hyperactive, motor stereotypies and attention seeking, with sleep disorders and toileting abnormalities (Dykens et al, 1997). Their SIB include biting, head banging and inserting objects into bodily orifices and pulling out finger or toe nails (Dykens & Smith 1998).

e) Lowe syndrome

This a rare genetic syndrome that causes physical and medical and mental handicaps .It is caused by a defective gene that results in the deficiency of phosphatidylinositol 4,5 biphosphate .It is known to cause delayed motor development, mental retardation ,seizures and self injurious behaviour (Kenworthy et al, 1993). Hypotonia, congenital cataract, renal

tubular dysfunction are also seen. Facial features like deep set eyes and frontal bossing are seen.

f) Rett syndrome

Rett Syndrome (RS) is a unique neurodevelopmental disorder which begins to show its effects in infancy or early childhood. It is seen almost exclusively in females, although it can occur rarely in boys. Rett syndrome is caused by a mutation in the MECP2 gene on the X chromosome. Loss of purposeful hand use; onset of repetitive non purposeful hand-washing movement; deceleration of head circumference; regression of language; ataxia; intellectual disability; self-injurious behaviour are the common features present (Ben Zeev Ghidoni,2007)

g) Joubert syndrome

This is a rare condition which causes cerebellar dysgenesis with autosomal recessive inheritance. Common physical features include motor retardation, hypotonia, rhythmic tongue protrusion, polydactyly, facial spasms, syndactyly, cystic kidney, ataxia and abnormal eye movements. Affected children are severely learning disabled. They show a characteristic 'episodic hyperpnoea'. This respiration mimics the panting of a dog. Some children with Joubert syndrome show autistic features including stereotyped hand movements. The condition has a poor prognosis. Individuals with Joubert syndrome

showed self-injurious behaviour in the form of self-mutilation, beating the head and biting body parts (Holroyd et al, 1991).

h) Tourette syndrome

Tourettes syndrome is a childhood onset neuropsychiatric disorder with multiple motor and vocal tics. Impulse control symptoms and SIB are commonly present. SIB occurs in upto 60% of patients with Tourettes syndrome (Eisenhauer et al, 1987, Robertson et al, 1989, Bertheir et al, 1996, Freeman et al, 2000, Cath et al, 2001). A variety of self injurious behaviour like compulsive skin picking , self hitting , lip and other self biting filing of the teeth, head banging and eye poking have been reported (Robertson et al, 1989).

4. NEUROCHEMICALS IMPLICATED IN SELF INJURIOUS BEHAVIOUR

Neurotransmitters and the balance among them have been studied extensively and documented in self injurious behaviour among children with these genetic syndromes or in mental retardation caused by non-specific factors. Irrespective of the genetic and non-genetic causes, endogenous opioids, dopamine, noradrenalin and serotonin have been implicated in SIB among humans and animals.

a) Opioids

The opioid hypothesis, the strongest model for SIB, postulates that pain and pleasure become intertwined in SIB and thus the system that evolved to protect the human body

from pain has seriously gone wrong. It appears that children with SIB have become addicted to their own neurotransmitter, which they have inadvertently learned to administer to themselves. It is suggested that children with SIB may initially damage themselves inadvertently and SIB is thought to be initially unrelated to the mechanism of endorphin release, but it becomes cumulatively reinforced through operant conditioning (Carr, 1977; Berkson, 1983). *Analgesia hypothesis* (Sandman & Datta, 1983) postulates that there are high levels of circulating β -endorphins in response to SIB overrides or significantly decrease the experience of pain because of some other cause. *Addiction hypothesis* postulates that endogenous opiates or endorphins are released in the brain following painful stimulation. These endogenous opioid peptides, which like heroin and morphine, bind to central nervous systems opiate receptors (Thompson et al, 1994). Repeated self-injury, with associated opioid release and occupation of opiate receptors may lead the self-injurious actions to come under control of the reinforcing effects of these ligands. Because discontinuing self-injury could induce an opiate-type abstinence syndrome, the individual may continue to self-injure, in part, to avoid withdrawal discomfort (Thompson et al, 1994).

Medication

It is theorised that if pain-producing behavior is reinforced by the release of endorphins onto the opiate receptors, then an effective means of placing this behavior on extinction would be to block the receptors (Richardson & Zaleski, 1983). Opioid antagonists actually have the best overall record and have been shown to be beneficial in reducing self-injurious behaviour in 40% to 60% of individuals (Sandman & Hetrick, 1995, Casner &

Weinheimer, 1996). Opioid antagonists have been shown to both reverse pain insensitivity and lower the pain threshold (Yanagida, 1978; Buchsbaum & Davis, 1977).

b) Dopamine

Repetitive, stereotypic motor movements driven by dopaminergic super-sensitivity or a dopamine regulatory defect might result in SIB (Goldstein & Anderson, 1985). Evidence points to dopaminergic abnormalities associated with repetitive, stereotypic responses, which include self-injury (Crews et al, 1993). These behaviours are consistent with a dopamine deficiency. Individuals with Lesch-Nyhan syndrome demonstrate a high prevalence of SIB, while persons with Parkinson disease do not although both diseases have dysfunctional dopamine neurons. Also, this difference suggests a link between age of neuronal loss and emergence of SIB (Hammock et al, 1995). This suggests the cause of some SIB may be due to the development of super sensitivity of D1 receptors as the result of early dopamine depletion.

Medication

Patients with dopamine as the putative neurotransmitter are predicted to respond to treatment with D1 dopamine blockers such as cis-flupenthixol or fluphenazine . There are no pure D1 blocking agents available for humans (Hammock et al, 1995) and flupenthixol/ fluphenazine are, in fact, a mixed D1-D2 blocker . It is also difficult to say if the success there has been appears to be due to the general sedative effects of neuroleptics (Hammock, 1995).

c) Noradrenaline

Norepinephrine, a transmitter generally associated with stress related fight or flight reactions have also been implicated in animal as well as humans engaging in SIB.(Haines et al ,1995). Increased norepinephrine sensitivity correlates with irritable-aggression and self-directed aggression in the form of SIB.

While NE acts as a neurotransmitter both in the CNS and peripherally, epinephrine only acts peripherally. Stress increases the responsiveness of the locus ceruleus, the main site of NE production and storage in the brain. This results in increased NE production and output in the amygdala, prefrontal cortex, hypothalamus, and hippocampus. Stress also directly activates the sympathetic nervous system (SNS). The SNS controls the “fight or flight” response, during which there is heightened anxiety, arousal and vigilance for expected imminent danger. Physiologic changes during SNS activation include increased heart rate, blood pressure, metabolic rate and alertness, sweating, and blood coagulation (useful if one is injured by a predator); blood flow away from the skin, gut and kidneys and towards the heart, brain and skeletal muscles (useful for running away from the predator).

Medication

A centrally acting alpha 2-receptor agonist causes a reduction in norepinephrine activity at the locus ceruleus. This is thought to be the mechanism for treating SIB as norepinephrine is a modulator of arousal states and directly affects dopamine and serotonin activity also.

d) Serotonin

Serotonin (5-HT), is believed to be involved in the regulation of many behaviours including aggression, arousal, pain sensitivity, and irritability (Brown et al, 1979; Valzelli & Bernasconi, 1979; Cleare & Bond, 1995), and could theoretically play a role in SIB.

Low central nervous system (CNS) 5-HT turnover rate, as measured by low cerebrospinal fluid (CSF) concentrations of the major metabolite of 5-HT, 5-hydroxyindoleacetic acid (5-HIAA) in CSF, has been observed to be correlated with high levels of aggression in both humans and nonhuman primates (Brown et al, 1979; Linnoila et al, 1983; Roy & Linnoila, 1988; Higley et al, 1996). Some patients who exhibit self aggressivity have low CSF 5-HIAA concentrations (Lopez-Ibor et al, 1985). If SIB is thought of as aggression turned toward oneself, it is possible that increasing CNS 5-HT function could decrease or eliminate SIB.

Medication

A recent study confirmed the presumption that serotonin reuptake inhibitors (SSRIs) can reduce impulsive aggressive behaviour (Reist et al, 2003). The effectiveness of serotonin reuptake inhibitors in the treatment of maladaptive behaviour, aggression and self-injury has also been shown in people with mental retardation (Branford et al, 1998; Davanzo et al, 1998).

5. PSYCHOLOGICAL COMPONENTS IN SIB

a) Setting events

Setting events are biologic influences that alter the existing relationship between environmental stimuli and the child's behavioural response, making the child predisposed for self-injurious behaviour. Allergic episodes, fatigue, constipation, or painful conditions such as otitis media and menarche can act as setting events. These biologic events thus replace the child's response to the familiar and so far acceptable antecedents with

new, unacceptable reaction such as self-injurious behaviour (Carr & Smith, 1995). In another study it was shown that seven out of eight of the participants showed at least one form of self-injurious behaviour was associated with a particular setting event. The study also demonstrated that the relationship between the setting events and environmental events was extremely variable across individuals (Moss et al, 2005).

Common medical causes of SIB include pain, seizures, delirium, GI distress, bowel irregularity, menstrual pain or other medical problems. Age-dependent medical problems can produce SIB, including angina, nerve root pain, peripheral neuropathy, degenerative joint disease, premenstrual syndrome, irritable bowel, sinusitis, allergies, menopause, and others. Therapy for minor medical problems, (e.g., antihistamines) can worsen confusion and behavioural abnormalities. Medication side effects such as muscle cramps from statin therapy, GI distress from anti-inflammatories, or akathisia produce or worsen SIB. Pain produced by ear infections, sinus infections, dental disease, headaches, (e.g., migraine, eye pain, glaucoma), can produce self-injurious behaviour that targets the head, face, and neck. Pain elsewhere in the body such as colonic distension, peptic ulcer disease, angina, degenerative joint disease, etc., may provoke or promote SIB of all types. Any patient with SIB requires a careful, complete medical evaluation. Face or mouth slappers require a dental exam. Eye pickers or gougers require a visit to the ophthalmologist. Because some individuals with intellectual disabilities cannot cognize or report symptoms, common health conditions can evolve into serious medical problems that produce significant distress and behavioural abnormalities. Dental abscesses, rectal impaction, sinusitis, etc., can develop in mentally retarded persons because the patient is unable to report early symptoms to clinicians.

b) Antecedents

The self-injurious behaviour is a complex process occurring due to a combination of factors, both neurochemical and psychological mechanisms. There are 5 major groups of psychological antecedents that precipitate self-injurious behaviour in children who are predisposed to self-inflicted wounds because of the neurochemical abnormalities and setting events. Negative reinforcement by escape-avoidance of demands occurs when requests to perform activities (such as self-care and academic tasks) that are beyond an atypically developing child's neurological and adaptive capacity. This kind of self-injurious behaviour is also reported when a child had been subjected to impoverished teaching environments and physical abuse associated with task achievement (Asmus et al, 1999). Positive reinforcement by attention maintains the self-injurious behaviour in children with disabilities who otherwise live in an environment with little interpersonal or other social interactions. Also, the attention-seeking self-injurious behaviour occurs when there is a mismatch between the child's need to have attention and the caregiver's ability to provide the required attention. Thus, self-injurious behaviour frequently draws the attention of the caregiver in the form of disapproving comments, redirecting to another activity, or sympathy (O'Reilly et al, 2000). Positive reinforcement by tangible reward sustains the self-injurious behaviour by way of gaining access to materials, situations, or activities that were not available to the child. Children who have limited repertoire of communication skills to attain the tangible rewards engage in self-injurious behaviour, especially when the wanted material or desired activity is removed or access to it is restricted. Also, observing other children's access to that particular object or being told that the article is contingent only on positive behaviours can trigger the self-injurious behaviour.

(Hagopian et al, 2001). Reinforcement by sensory consequence is precipitated when the child tries to mask an existing painful condition (such as increased intracranial pressure from hydrocephalus) with self-injurious behaviour (Breau et al, 2003) or self stimulates when there is sensory deprivation (such as pressure on the optic nerve head in children with blindness) with self-inflicted injuries (Linderman & Stewart, 1999). The self injurious behaviour can also serve multiple functions for children with atypical development, and therefore, an antecedent-behaviour-consequence analysis for self injurious behaviour is often required to elicit the many functions of this behaviour as described.

c) Consequence

In consequence management, 2 principles are essentially adhered to: first, the least intrusive procedures are used as the first line of management to ensure an ethical approach, and second, the management should be inclusive of a functional alternative for the self injurious behaviour. Based on these principles, there are 4 levels of control that can be prescribed to control SIB. Level I consequence management for self-injurious behaviour includes using diverse differential reinforcement strategies namely: differential reinforcement of low rates behaviour (DRL), differential reinforcement of other behaviours (DRO), differential reinforcement of incompatible behaviours (DRI), and differential reinforcement of alternative behaviour (DRA). Level II employs the extinction principle and terminates the reinforcement. Level III utilizes procedures that advocate removal of desirable stimuli such as response coast and time-out. Level IV comprises overcorrection procedures and various aversive techniques (Alberto & Troutman, 1990).

6. ASSESSMENT FOR SELF INJURIOUS BEHAVIOUR

We briefly review the assessment of SIB; the various ways of assessment of self injurious behaviour and the possible differential diagnosis to be considered are discussed in detail in the SIB literature (Richard et al, 2005).

a) Clinical assessment

New onset SIB, reoccurrence of previous SIB or dramatic increased symptoms of SIB requires a detailed medical, psychiatric, and neurological evaluation (Kastner et al, 2001; Ryan & Sunada, 1997; Silka & Hauser, 1997). However, five dimensions have to be assessed clinically for formulating a therapy strategy, namely:

- i. Setting event
- ii. Mode of injury
- iii. Frequency of injury
- iv. Body site preference
- v. Antecedents and consequence for SIB

Approximately 80% of the reported self injurious behaviour was disproportionately directed towards the head and the hands. Three quarters of the head directed self injury was located in the front of the head. 83% of the hand directed self injury was located on the back of the hands (Symons & Thompson, 1997). 32% of the body sites towards which self injury was directed were located on stimulation produced analgesia body sites, probably pointing towards an opiate hypothesis for the self injurious behaviour.

Biting was the most commonly reported form of self injury with the fingers and back of the hand was disproportionately targeted as the most prevalent self injury body site (Symons et al, 2003)

Research suggests that body sites targeted by SIB are non-randomly distributed across the body. Self injury sites may overlap with Acupuncture Analgesia sites, which have been linked to the opioid hypothesis of SIB (Symons & Thompson, 1997)

b) Assessment with instruments

Specific SIB measures and SIB as a subscale of composite behavioural problems measures have been validated and used in the evaluation of SIB.

- i. Self-Injury Trauma Scale (Iwata, 1990): The Self-Injury Trauma Scale permits differentiation of self-injurious behaviour according to topography, location of the injury on the body, type of injury, number of injuries, and estimate of severity.
- ii. Behaviour Problems Inventory (Rojahn et al, 2001): This instrument rates for self-injurious, stereotypic, and aggressive/destructive behaviour in mental retardation and other developmental disabilities.
- iii. Nisonger Child Behaviour Rating Form (Aman et al, 1996): This instrument measures eight domains namely compliant / Calm behavior, adaptive/social behaviour (positive-social behaviour) and conduct problem, insecure /anxious hyperactive, self-Injury /stereotypic, self-isolated /ritualistic, overly sensitive (problem behaviour)

iv. Diagnostic Assessment for the Severely Handicapped-II (Matson et al, 1997):

This also is a composite measure that measures SIB among many other psychopathologies.

7. PHARMACOLOGICAL MANAGEMENT

While there is no well-established "drug of choice" for SIB, the identification of specific subgroups of SIB patients and associated symptoms permits the rational selection of medication. (a) A malfunction of the opioid neuropeptide regulatory system; (b) A central nervous system dopaminergic abnormality in the nigrostriatal system; (c) A central nervous system serotonergic dysfunction (d) A central nervous system noradrenergic dysfunction.

Eighty percent of subjects were reported to improve relative to baseline (i.e., SIB reduced) during naltrexone administration and 47% of subjects SIB was reduced by 50% or greater (Symons et al, 2004). For self mutilatory behaviour, naltrexone is administered orally at 0.5 mg/kg/d and increased after 10 days to 1 mg/kg/d. The dosage is raised until a clinical end point is reached or to a maximum of 2 mg/kg/d (Symons et al 1999, Symons et al 2004).

Super-sensitivity of dopaminergic neurons in the nigro-striatal system is thought to play a role in the genesis of severe self-injurious behaviour in some people with learning disabilities. The therapeutic action of fluphenazine and clozapine were documented (Schroeder et al, 1995). Following this there has been accumulating evidence that dopamine blocking medication do have a beneficial effect on a subgroup of children with SIB. Repetitive stereotypic self-injurious behaviour is treated with an atypical

antipsychotic such as oral risperidone up to 2 mg/d or a typical antipsychotic such as oral haloperidol of up to 4 mg/d. (Aman, 1993)

For high-rate self-injurious behaviour, a selective serotonergic reuptake inhibitor such as fluoxetine is administered at 10 mg/d for children younger than 8 years of age, and for older children, up to 20 mg/d to control the deviant behaviour (Aman ,1993)

Self-injurious behaviour occurring with agitation when SIB is interrupted can be managed with lithium, given orally and the serum level maintained below 1 mEq/L to avoid toxicity. Alternatively, β -adrenergic blocking medication like propranolol can be started at 10 mg 3 times a day orally and may be increased every 3 days to reach a maximum of 520 mg/d (Aman ,1993). Also, partial α 2-adrenergic agonists such as clonidine may be prescribed at a maximum dose of 0.4 mg/d (Mc Cracken et al, 2002).

8. PSYCHOSOCIAL TREATMENTS

The psychosocial management includes both antecedent and consequence management.

The management for antecedents has already been discussed. In consequence management, 2 principles are essentially adhered to: first, the least intrusive procedures are used as the first line of management to ensure an ethical approach, and second, the management should be inclusive of a functional alternative for the self-injurious behaviour. Based on these principles, there are 4 levels of control that can be prescribed to control self injurious self-injurious behaviour. Level I consequence management for self-injurious behaviour includes using diverse differential reinforcement strategies namely: differential reinforcement of low rates behaviour (DRL), differential reinforcement of other behaviours (DRO), differential reinforcement of incompatible behaviours (DRI), and differential

reinforcement of alternative behaviour (DRA). Level II employs the extinction principle and terminates the reinforcement. Level III utilizes procedures that advocate removal of desirable stimuli such as response cost and time-out. Level IV comprises overcorrection procedures and various aversive techniques (Alberto & Troutman, 1990).

9. BURDEN ASSOCIATED WITH SELF INJURIOUS BEHAVIOUR

Morbidity and mortality associated with SIB is high as it can range from a painless rubbing to disastrous injurious behaviours like self-mutilatory behaviour. It is a problem that requires resource-intensive treatment with special training in identifying, diagnosing it from a biopsychosocial perspective and thus requires a multidisciplinary-multimodal management approach, in severe cases as inpatient. It is documented to cause significant burden of care and burn out among clinicians as well as social costs and social exclusion among children with atypical development who are already at a risk of being excluded (Felce et al, 2000). Given the extreme emotional and physical burden that self-injurious behaviour inflicts on patients and families, adding to the existing research on the environmental and biological underpinnings of self-injurious behaviour is a worthwhile goal.

10. CLASSIFICATIONS IN SELF INJURIOUS BEHAVIOUR

SIB is a very heterogeneous condition in many dimensions and so are the classifications available. Several schemes have suggested for categorising SIB, but there is no consistent classification system.

a) Classification based on behavioural control (Favazza & Rosenthal, 1993).

This was the most widely used schema and divides SIB into 4 major categories:

- i. Stereotypic SIB

- ii. Major SIB
- iii. Compulsive SIB
- iv. Impulsive SIB

Complex forms of SIB such as eye poking as with tics (Robertson et al, 1989) represented stereotypic subtype, and repetitive hitting behaviours represent compulsive subtype. The definition for major and impulsive is unclear. Also, separating compulsive behaviour stereotypic behaviour can be difficult and treatment practices for those symptoms also fall into the gray area. Although it was widely used, there is significant overlap between these categories in the types of SIB that are included, the severity of symptoms, and characteristics such as rate or pattern of behaviours (Favazza & Simeon, 1995).

b) Classifications based on clinical severity (Simeon & Favazza, 2000):

This is based on the severity of the injury caused by the individual.

- i. Moderated SIB: Rubbing and mouthing
- ii. Severe SIB: Disastrous self-mutilation

It was postulated that from a clinical perspective, classification and treatment based on severity of self injurious behaviour would be a simpler approach than trying to distinguish accurately between such complexities. Accordingly SIB was classified into moderate SIB and severe SIB. Moderate SIB included the compulsive and stereotypic categories as proposed by Favazza et al and severe SIB included the major and impulsive categories

c) Classification based on injury-associated behaviour topography:

Topographically there are 4 different subtypes of self injurious behaviour categorized based on the site of the wound and other behaviours associated with SIB.

i. Extreme Self Inflicted Injury (Type I)

Extreme self inflicted injury is characterized by tissue damage such as auto amputation, bony injuries, and injuries resulting in loss of consciousness, or extensive laceration to the extremities or to the head. Extensive laceration is defined as being more than 3 x 3 cms. Such self mutilatory behaviour is seen secondary to severe biting and chewing behaviour as well as result in deep wounds and scarring.

ii. Repetitive or Stereotypic SIB (Type II)

Repetitive or stereotypic self injurious behaviour presents as repeated rubbing of body parts together or against other surfaces and recurrent mouthing of extremities resulting in callous formation due to mechanical abrasion or repeated wetting of skin. Injuries are usually seen in the lateral side of the limbs, bony prominences, or facial structures such as the nose and ears. The duration between the injurious behaviours is as short as 1-10 seconds within each episode. These injuries are less serious, and are often seen in concurrence with non injurious motor stereotypies.

iii. Self Injurious Behaviour With Agitation (Type III)

Self injurious behaviour with agitation results in behaviour such as banging the head or limbs and self hitting. When the SIB is stopped there are concomitant symptoms of agitation (autonomic hyper arousal) such as screaming, aggression, pacing, sweating, hyperventilation and tachycardia. The self injurious behaviour rates may vary but generally is low. Concurrent history of anorexia and insomnia may be present.

iv. Self Injurious Behaviour with agitation when interrupted (Type IV)

A variety of self injurious behaviour at a rate of more than 100 times per hour is noted. The self injurious behaviour recurs within 30 seconds of completing any activity and usually when prevented does not result in agitation.

11. CLASSIFICATION ALGORITHM IN SIB

Simple *classification algorithms*, including those designed to aid clinical diagnosis, require no action on the part of the user other than observation, patient examination and the noting of test results. Algorithms that include both diagnostic and treatment modalities are referred to as *management algorithms*. The main structural difference between management algorithms and classification algorithms is the presence of boxes (nodes) containing instructions (e.g., “Begin rescue breathing”). In contrast to question nodes in classification algorithm (which always have two exit arrows - one for “yes” and one for “no”), instruction nodes have only one exit arrow in management algorithm.

a) Advantages of using algorithm

- i. Algorithms conveniently convey the scope of a guideline, summarizing at a glance the types of patients covered and not covered, as well as the range of management decisions and strategies addressed. In addition, algorithms serve to organize the guideline, enabling the user to see the “big picture” with respect to how the different sections of guideline relate to each other.
- ii. Algorithms have been shown to result in faster learning, higher retention, and better compliance with established practice standards than standard prose text. One of the most valuable features of algorithms is that they identify situations in which testing is unnecessary. Too often, testing is carried out irrespective of whether the

subsequent management strategy would change as a result of the tests. With the algorithm approach, testing is incorporated in the flow of patient evaluation only if “downstream” management strategies depend on test results.

- iii. Properly constructed algorithms help guideline developers specify appropriate indications for particular management strategies.
- iv. Algorithms are readily translatable into computerized formats, which permit the application of guideline recommendations to quality assessment and utilization review activities. Indeed, computerization of guidelines is dependent on the use of algorithmic formats to illustrate decision making and appropriate care.
- v. Algorithms permit the sort of modelling and testing required to explore the impacts of changing assumptions about outcomes, costs, and preferences on the structure and content of clinical guidelines. Critical branches or pathways can be selected and guideline panels presented with a range of differing assumptions to determine whether and to what extent the management recommendations contained in those branches or pathways change in light of changing assumptions.

b) Paucity of classification algorithm in SIB

Judgments of expected benefit of any algorithm are tricky, of course, and in effect constitute outcome predictions with their own degree of sensitivity, specificity, and predictive value. Outcome studies are essential if these judgments are to be made as accurately as possible.

Aims & Objectives

CHAPTER III

AIMS AND OBJECTIVES

1. Derive and explore if there are clinically four clusters of Self-injurious behaviours in the study sample as suggested by the theoretical model.
2. Estimate the diagnostic accuracy of the classificatory algorithm for the sub-classification of self injurious behaviour against the existing gold standard.

Methodology

CHAPTER IV

METHODOLOGY

RESEARCH DESIGN

A prospective, cross-sectional research design was used to derive a cluster based typology of Self-injurious behaviours from the literature evidenced Self-injurious behaviours algorithm. The cluster-based classificatory algorithm, from the typology, for the sub-classification of self injurious behaviour was validated against the existing gold standard.

SETTING OF THE STUDY AND POPULATION

The study population was children from the facility for children with mental retardation at Christian Medical College, Vellore. Participants were children with mental retardation enrolled either for assessment, treatment in the day care therapy program or residential therapy program. Participants from this centre were recruited during the years July 2006 to June 2007 using specific selection criteria.

SELECTION CRITERIA

Inclusion criteria

1. Children and adolescents defined as anyone ≤ 19 years (UNICEF, 1992).
2. With atypical development defined as mental retardation (DSM-IV-TR; APA, 2000).
3. With self injurious behaviour defined as self directed repetitive behaviour exhibited by a person that results in tissue damage (Tate & Baroff, 1966).

Exclusion criteria

1. Children on psychotropic medication that affects SIB.
2. Informant living with the child for less than 3 months.

SAMPLING TECHNIQUE AND STUDY SAMPLE

Purposive sampling was used to select the study samples. Children who fulfilled the selection criteria were included for the study till the required sample size was recruited. Same number of children and adolescents who were matched for the gender and IQ were included as controls. The controls were primarily included to study the construct of SIB.

SAMPLE SIZE

The sample size required to estimate a sensitivity of 80% with 90% confidence interval and an expected drop-out rate of 20% were calculated using the formula $4pq/d^2$ and was determined to be 77.

DATA COLLECTION TOOLS

1. Socio demographic data collection proforma (Appendix I)

This data collection proforma was prepared specifically for this study and it consists of the socio-demographic data of the participants and their parents. It also includes the information regarding the person intellectual functioning, adaptive behaviour, and details on SIB.

2. Self Injurious Behaviour Symptom based on literature

The symptom checklist was formed by compiling all the 24 symptoms that have been described as part of SIB I to SIB IV in the literature.

Table 1: SIB symptom based on literature

<i>Dimensions of SIB</i>					
<i>Type of injury</i>	<i>Mode of injuring</i>	<i>of Body topography</i>	<i>Rate of injury</i>	<i>of Agitation</i>	<i>Sequae</i>
Auto amputation	Mouthing/wetting	Eye	>100/hour	None	Callosity
Bony injuries	Repeated rubbing	Mouth/buccal cavity	Slow rate	If SIB interrupted	Extensive Laceration
Injury with LOC	Biting	Injury to face			Scarring
	Slapping	Injury to head			
	Banging	Injury to extremities			
	Pulling	Injury to side of body			
	Poking				
	Picking				

The 24 symptoms were divided in to 6 subgroups of type of injury, mode of injuring, body topography, rate of injury, agitation, injury sequae (Table1).

3. Theory-based algorithm

Based on the 24 symptoms a new clinical algorithm for classifying SIB was formed (Russell, 2006) for validation. The classificatory algorithm is a follows:

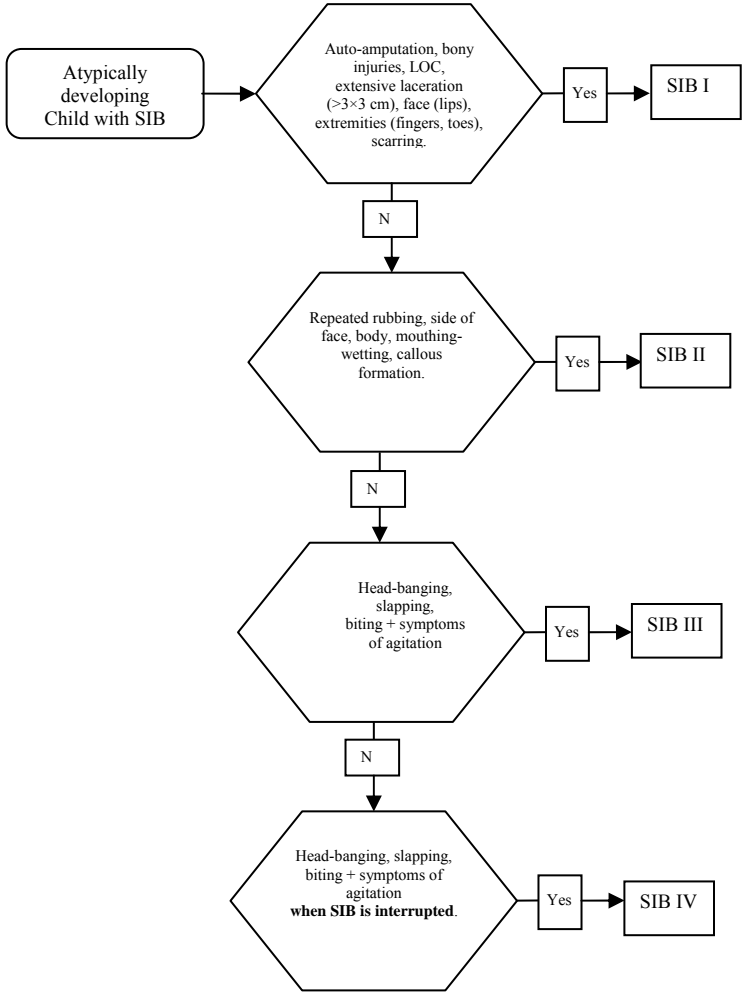
SIB Type I includes major mutilatory self-injuries.

SIB Type 2 includes multiple repetitive SIB with callous formation.

SIB Type 3 includes high rate SIB

SIB Type 4 includes SIB with agitation if SIB is stopped.

Figure 1: The literature evidenced clinical algorithm used for deriving the cluster based Algorithm for validation.



4. Reference measure

The *gold standard* measure will be the standard clinical diagnosis (sub-classification) that is made by the multidisciplinary treating team of about 10 clinicians based on their collective knowledge/ trial and error for SIB, the existing methods all across the world, and the final classification that has resulted in treatment response to medication.

DATA COLLECTION PROCEDURE

All children and adolescents attending the facility and orphanage were screened for any SIB using the SIBSC by the primary investigator, a qualified psychiatrist. If the participant has symptoms suggestive of SIB, the primary investigator would use the clinical algorithm and classify the child having on or multiple types of SIB (SIB I to IV type and multiple type). The screening and classification of SIB by this investigator is done independently from the classificatory diagnosis made by the treating team. Also, the screening and classification of SIB was completed within one week of the participant enrolling for assessment or treatment.

The multidisciplinary treating team consisting of about 10 clinicians blinded to the diagnosis made by the person who administered the checklist and index algorithm made the reference-standard diagnosis that provided the sub-classification of SIB.

ETHICAL ISSUES

1. Permissions were obtained from the department of Psychiatry and orphanage before conducting the study.
2. Approval of ethical clearance from the local Institutional Review Board was obtained before conducting the study.
3. Verbal assent was obtained from the child or adolescents and written, informed consent from the primary caregiver.
4. Measures were taken for maintaining confidentiality of the interview responses.

DATA ANALYSIS

The statistical analyses included mean and standard deviations, Chi-square test with Yates correction and Independent Student's t test or Mann-Whitney U test for describing the participants' characteristics.

Chronbach's alpha and factor analysis were conducted to explore the internal consistency of items constituting the dimensions of SIB, and principal component analysis was done for item reduction of the SIB symptoms. Exploratory factor analysis with varimax rotation was used to determine the underlying dimensions of SIB. Once these dimensions were validated, cluster analysis was performed to explore the possibility that children form homogeneous groups based on the importance of the SIB symptoms.

Hierarchical cluster analysis procedure was performed to identify the SIB clusters among the children with atypical development. Standardized clustering variables (Z-scores), Squared Euclidian Distance and the Ward's method for linking were applied in the cluster analysis. Agglomeration coefficient was calculated to support the dendrogram to select the appropriate number of clusters. Characterisations of clusters were done with descriptive analysis.

Step-wise discriminant analysis was conducted to explore the discriminant power of each of the SIB symptom in the clusters, to identify the SIB symptoms that contribute the most to the discrimination of each cluster, how far away are the clusters from centre of each cluster mean and the predictive ability of the identified cluster model as well as the

goodness of fit of the discriminant model. A significance level of 0.05 and 2-tailed tests were used unless otherwise noted. Data were analyzed using SPSS 12.0.

All these data analysis methods are further described along with their results and discussion sections for coherent reading.

Results

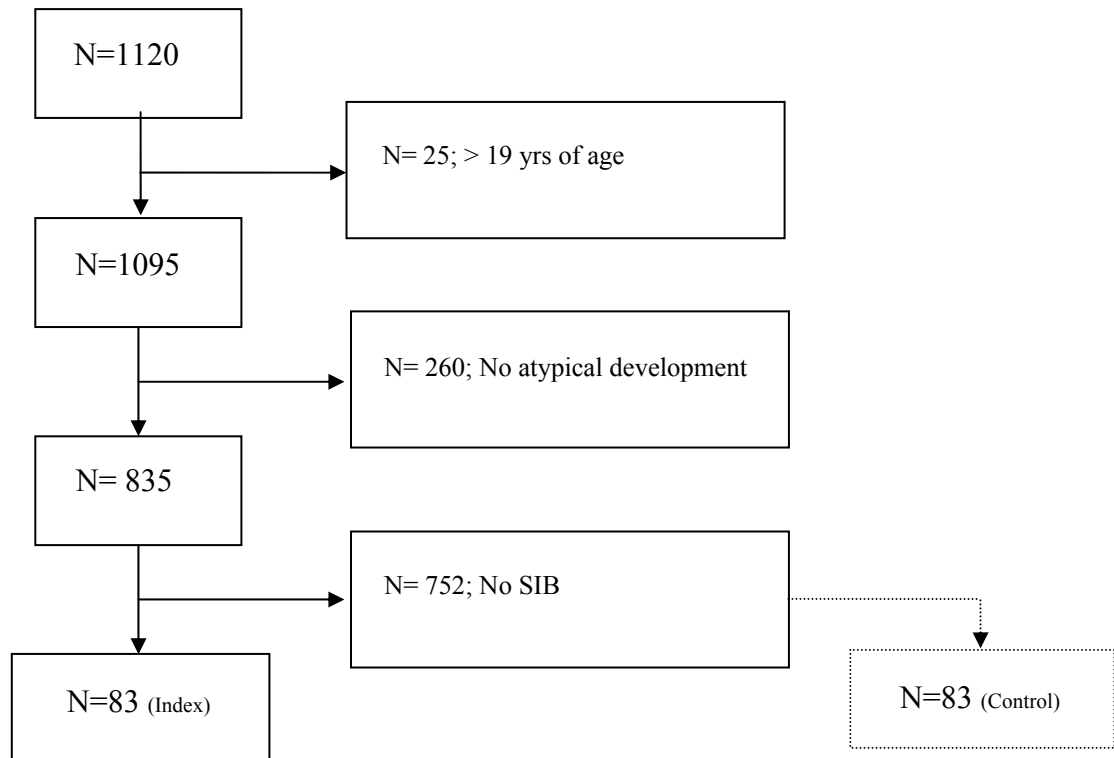
CHAPTER V

RESULTS

I. Participant flow

Among the 1120 children who enrolled in the facility for various programs in the study period and satisfied the selection criteria, 83 had SIB and formed the Index group and another 83 children matched for chronological age and gender during the same 1 year period formed the control group (Figure 2).

Figure 2: Flow chart summarising the index and control groups.



II. Participant characteristics

Table 2: Participant characteristics for the total sample and between SIB and non-SIB groups.

Variable	Total N=166	SIB group N=83	Non-SIB group N=83	Statistics χ^2/t ; df	P value
Chronologic age	7.90(4.59)	7.10(4.08)	8.69(4.96)	-2.24, 164	0.02
Social age	3.08(2.38)	2.42(1.77)	3.52(2.63)	13.21 ; 137	0.007
IQ	31.82(16.97)	33.32(16.61)	30.80(17.27)	0.73; 99	0.9
Gender-					
Male	118	59	59	0.00 ; 1	1.0
Female	48	24	24		
Psychological comorbidity					
Yes	46	32	14	9.74 ; 1	0.002
No	120	51	69		
Medical comorbidity-					
Yes	86	44	42		
No	80	39	41	0.09 ; 1	0.75

The SIB and the non SIB group statistically significantly were different in their chronological age, social age, and psychological comorbidity. The children in the SIB group were chronologically younger and had lower social age along with higher prevalence of psychological comorbidity (Table2).

Table 3: Participant characteristics between the literature based SIB groups.

Variable	SIB I N=4	SIB II N=17	SIB III N=46	SIB IV N=3	Stat χ^2 / F; df	P
Ch. age	5.02(2.15)	7.26(4.85)	6.91(3.96)	6.39(1.52)	0.34; 3	0.7
Social age	1.88(1.35)	2.66(2.08)	2.23(1.66)	0.65	-2.8, 137	.001
IQ	27.00(14.14)	22.88(14.17)	37.95(15.84)	27.50(23.33)	1.94; 3	0.1
Gender						
Male	3	10	35	1	3.79; 3	0.2
Female	1	7	11	2		
Psy.comor						
Yes	1	4	23	1	4.16; 3	0.2
No	3	13	23	2		
Med.comor						
Yes	2	9	26	2	0.26; 3	0.9
No	2	8	20	1		

The participant characteristics were not statistically significantly different between the four SIB groups as noted in Table 3.

III. Prevalence of SIB based on the literature based model

The total prevalence of SIB in the study population was 9.94% (83/835). The SIB type I prevalence was 4.82% (4/83), SIB type II was 20.48% (17/83), SIB type III was 55.42% (46/83), SIB type IV was 3.61% (3/83), SIB- mixed type was 12.66 (13/83).

IV. Construct of Self-Injurious Behaviour

Internal consistency

Although validity has not been fully established for these SIB symptoms, they have been listed in numerous studies. The internal consistency (reliability coefficients) for these measures ranged from .07 to .46 (see Table 4).

The measures of internal consistency suggested that item homogeneity was not present among the SIB items and they did not measure a unified construct. This multidimensional structure of SIB was analysed with an exploratory factor analysis, the factor analysis also helped in item reduction of SIB items.

Factor structure

The factor structure demonstrated that the SIB symptoms were indeed not homogenous but in effect had a 4-factor structure: biting, extremities at a high rate formed *Factor 1*, banging and mouthing the head and peri-oral area with callous formation created the *Factor 2*, picking of body-side with onset of agitation if SIB is stopped formed *Factor 3*, poking of the eye formed the *Factor 4* (Tables 5). These four factors explained 51% of the variance with Factors 1, 2, 3 and 4 explaining 15, 13, 12 and 10% of the variance respectively.

Table 4: The internal consistency of the SIB symptoms^a

	SIBSC symptoms	Number of items	Chronbach's alpha
1.	Modality of injury	8	0.40
	Mouthing/wetting		
	Rubbing		
	Biting		
	Slapping		
	Banging		
	Pulling		
	Poking		
	Picking		
2.	Site of injury	6	0.46
	Eye		
	Mouth		
	Face		
	Head		
	Extremities		
	Body side		
3.	Sequae to injury	2	0.07
	Laceration /Scarring		
	Callus formation		
4.	Rate of injury	1	-
	SIB High rate (SIB >100)		
5.	Onset of agitation if injury stopped	1	-
	Agitation if SIB Stopped		
	Total SIBSC	18	0.01

^a= Rate of injury and Onset of agitation if injury stopped are single item SIB dimensions and hence internal consistency not calculated. Hence these two dimensions were included only in the internal consistency calculation for all the SIB items (scale level).

Table 5: Four factor solution for clusters of 19 SIB Symptoms in children with atypical development.^{a,b}

SIBSCL symptoms ^c	Component			
	Factor 1	Factor 2	Factor 3	Factor 4
Mouthing/wetting	.23	.75	-.13	-.13
Rubbing	.06	.02	-.06	-.04
Biting	-.80	.13	-.11	-.02
Slapping	.17	-.26	.05	-.01
Banging	.27	-.47	-.26	-.29
Pulling	.06	-.10	-.05	-.05
Poking	.07	-.01	-.01	.88
Picking	.03	.00	.83	-.00
Eye	.07	-.02	-.01	.89
Mouth	.24	.81	-.15	-.13
Face	.04	-.04	.18	.03
Head	.37	-.62	-.31	-.33
Extremities	-.80	.13	-.11	-.02
Body side	.07	-.07	.46	.10
Laceration /Scarring	.03	-.01	.38	.07
Callus formation	.02	.79	-.18	-.10
SIB High rate (SIB >100)	-.69	-.07	-.04	-.04
Agitation if SIB Stopped	-.01	.04	.76	-.19

Note: N=163 SIB children.

^a Principal component analysis. Rotation method: Varimax with Kaiser normalisation.

^b = Loadings > 0.40.

^c= SIB symptoms of Injury with lose of consciousness; bony injuries and auto-amputation were not noted in the sample and therefore did not enter the factor analysis.

Figure 3: Scree plot showing the factors with an eigen value of 1.5.

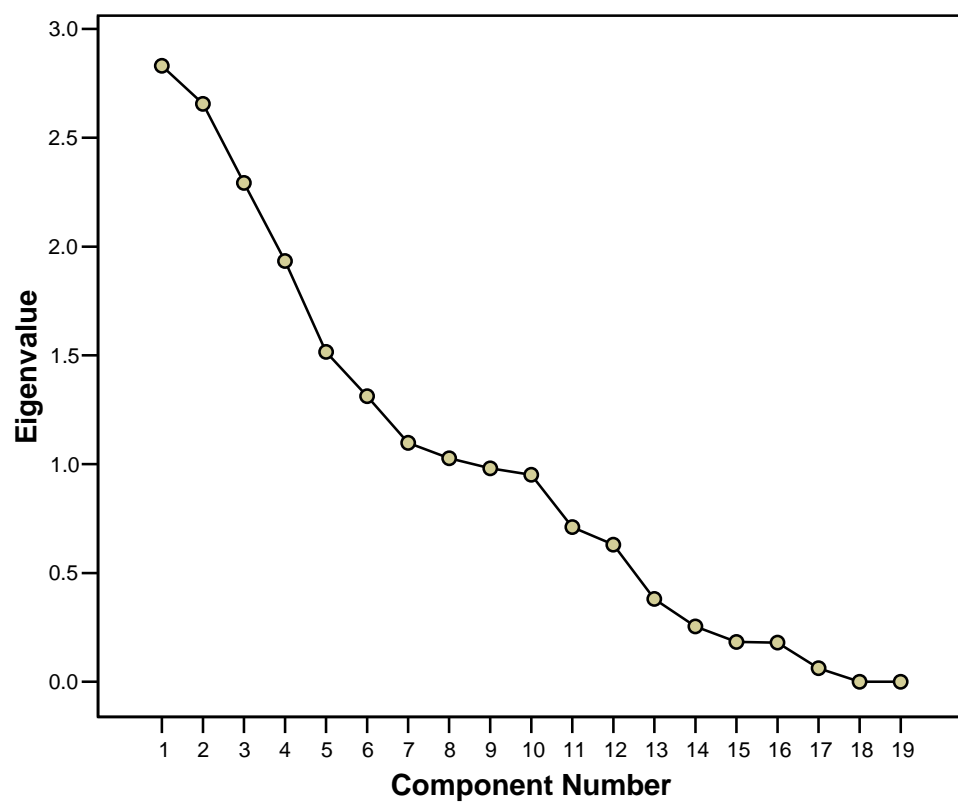


Table 6: Item reduction of SIB symptoms with the final 13 items loading to the 4-designated factors.

Items that loaded	Designation of the factor
Biting as mode of injuring Extremities being injured SIB rate of > 100/hour	High rate limb biting (3 items)
Mouthing, banging as mode of injuring Buccal cavity-mouth, head being injured Resulting in callous formation	Head banging and mouthing with callosity (5 items)
Picking as mode of injuring Sides of body being injured Agitation if SIB is interrupted	Torso picking with agitation when SIB is stopped (3 items)
Poking as mode of injuring Eye being injured	Eye poking (2 items)

Item reduction

The 24 SIB symptoms (items) were reduced to 21 as the endorsement rate for auto-amputation, bony injury and injury with LOC was zero as they were noted. They were deleted from the symptom list leaving 21 items.

Items of mouthing and wetting were as well as laceration and scarring were clubbed together as were assessing the same symptom and thus 19 items entered the item and factor analysis for item reduction.

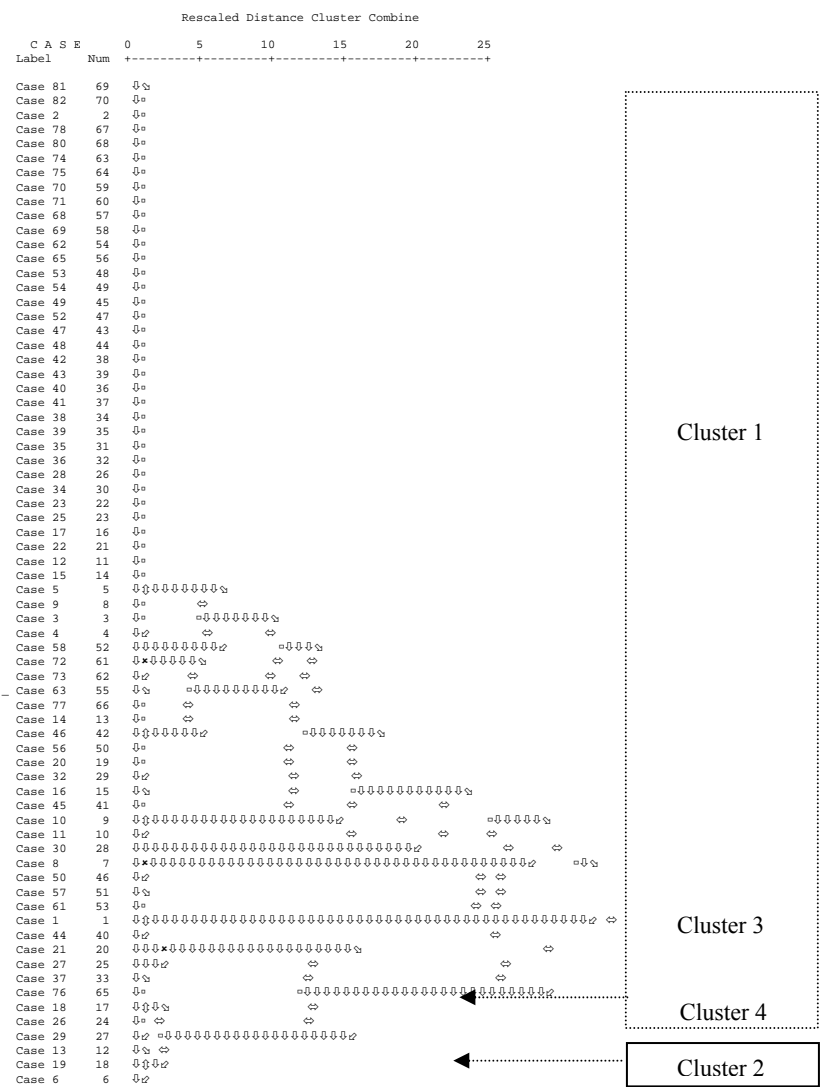
When a loading threshold of 0.4 was used for item loading, from the total of 19 items only 14 factors loaded on to the four factors as seen in the Table 5 and 6. These reduced number of items, validated for their factor structure formed the Self Injurious Behaviour Checklist (SIBCL). These 14 items formed the measure (independent variables) used for cluster derivation and discrimination of clusters.

V. Development and Identification of number of SIB symptom clusters

After the predictor variables were tested and found to meet the basic assumptions for linear modelling, the cluster analysis was continued. A visual analysis of the dendrogram supported by a percentage change in the agglomeration coefficient determined four clusters to be appropriate (see Figure 2 and Table 7).

Table 6 presents agglomeration coefficients for the first sixteen cluster solutions. Data revealed a small percentage of change in coefficients from the fifth to sixteenth cluster solutions. Thus relatively trivial changes in the agglomeration coefficient were observed until the stage in which five clusters were reduced to four. The large increase in the agglomeration coefficient (12.6%) at that point suggested that two very distinct clusters had been combined. At this stage, an increase in the agglomeration coefficient change exceeding 3% indicated a large jump in cluster variability, suggesting that dissimilar clusters were being combined (Hair et al, 1995).

Figure 2: Dendrogram output from the hierarchical cluster analysis of SIB symptoms.



The figure can be read from left to right as a summary of the clustering process. At each step, starting with each child as his/her own cluster, the most similar clusters are amalgamated at each stage. Cases are listed along the y-axis, while the x-axis indicates a rescaled measure of multivariate similarity in behavioural performance. When clusters are less similar to their nearest neighbours, the vertical distance between the formation of the cluster and its amalgamation will be larger. The 4-cluster solution is emphasized by the boxes at the right side of the figure.

Table 7: Agglomeration coefficients and percentage of change across steps in cluster analysis.

No. of cluster	Agglomeration Coefficient	% Change in Coefficient to the next level
16	.00	
15	8.38	0.93
14	17.18	0.98
13	27.66	1.16
12	47.23	2.18
11	69.25	2.45
10	93.64	2.71
9	126.45	3.65
8 ^b	189.09 ^b	6.98 ^b
7	252.57	7.07
6	317.69	7.26
5	390.67	8.13
4 ^a	503.69 ^a	12.59 ^a
3	619.57	12.91
2	751.01	14.65
1	897.00	16.27

^a = Jump in percentage change between a four and five cluster solution indicates that a four cluster solution is the best.

^b = Jump in percentage change between a nine and eight cluster solution indicates that it can be an alternative solution.

VI. Cluster characterisation and symptomatology within clusters

The cluster analysis produced 4 groups as expected with 4 cases in Cluster I, 48 cases in Cluster II, 10 cases in Cluster III and 8 cases in Cluster IV. This cluster analysis produced four groups that seemed partly consistent with the previous findings: Painless SIB (n = 4), Violent and painful SIB (n = 48) youths, SIB with high rate behaviour (n = 10), and SIB with onset of agitation when SIB is prevented (n = 8). The four clusters were named according to their average clinical characteristics.

Cluster I: Painless Self-injurious behaviours. Members of this group comprised 5.7% of the sample. They were characterized by mouthing as the modality of injuring self with higher peri-oral injuries related to mouthing resulting in painless injuries and callous formation than children in all other clusters. They resembled children in that the peri-oral injuries were also noted in *Cluster II* and callous formation in *Cluster II* and *Cluster III* (see Table 7). However, all the three SIB symptoms namely mouthing as a modality of injury, peri-oral area as the site of injury and callous formation significantly differentiated the *Clusters* (see Table 8).

Cluster II: Violent-painful Self-injurious behaviours. Individuals in Cluster II comprised 68.6% of the sample. Members of this cluster were characterised by multiple modalities of injuring self and multiple site in the body, all resulting in significant pain. Banging and poking as the modality of injuring self as well as injuring head and eye as the preferred site was noted only among this cluster member and thus differed from other clusters. They resemble Cluster I in sharing peri-oral injuries and callous formation as well as by sharing callous formation with Cluster III (see Table 7). The only symptom that was significantly able to differentiate among clusters was injuring mouth and callous formation.

Table 7: Distribution of SIB symptoms within clusters

SIBSCL	Cluster 1 (N=4)	Cluster 2 (N=48)	Cluster 3 (N=10)	Cluster 4 (N=8)
Mouthing	4	0	0	0
Biting	0	0	9	0
Banging	0	13	0	0
Poking	0	2	0	0
Picking	0	0	0	5
Eye	0	3	0	0
Mouth	4	2	0	0
Head	0	25	0	0
Extremities	0	0	9	0
Body side	0	0	0	6

Scarring	0	0	0	1
Callus formation	4	9	3	0
SIB >100	0	0	2	0
Agitation if SIB Stopped	0	0	0	1

Cluster III: High-rate self injurious behaviour. This group comprised 14.3% of the sample. These individuals had biting as the modality of injuring with extremities and parts of face as the preferred site of injury with callous formation. Also only this group had high rate of SIB among them, at a rate of more than 100 injuries per hour (Table 7). Members of this Cluster shared the symptom of callous formation with *Clusters I* and *Cluster II*. All these 4 SIB symptoms were significantly more in this cluster (Table 8).

Cluster IV: SIB with onset of agitation when SIB is prevented. Members of this cluster comprised 11.4% of the sample and were characterized by picking as the modality of injuring, preferentially the side of the body with onset of agitation when SIB is prevented and scarring. These characteristics of the members were not shared by members of any other clusters (Table 7 and 8).

VII. Cluster assignment

To check these clusters for accuracy, a four-by-four chi-square analysis cross-tabulated the children identified by group using cluster analysis and those children identified by theoretical models (Mace and Mauk, 1999). The chi-square value of 19.31 ($P = .02$) indicates that, although there are slight differences in group membership, the two sets of groups are meaningfully significant. The Cramer's V ($V = .30$, $P = .02$) suggests an association between the four sets of groups (Table 8). Although there are differences,

the literature based SIB groups are not significantly different from the groups derived using cluster analysis. This helps confirm that the groups identified by the cluster analysis procedure are similar to the criterion provided by theoretical model.

Table 8: Comparison of literature based algorithm by cluster groups in identifying SIB^a

		Theory based SIB				Row total
		Self mutilation	Repetitive	High rate	Agitation when interrupted	
Cluster groups	I	0	4	0	0	4/5.7%
	II	3	9	34	2	48/68.6%
	III	0	4	6	0	10/14.3%
	IV	1	0	6	1	8/11.4%
	Column total	4/5.7%	17/24.3%	46/65.7%	3/4.3%	70/100%

^a = $\chi^2 = 19.31$ (df=9), P=0.02; Cramer's V = 0.30, P=0.02.

Chi-square tests were conducted to examine if all selected clustering variables differentiated groups. Results revealed that three variables namely banging and poking as the modality of causing the injury and eye as the site of injury did not distinguish groups (different SIB clusters) (Table 9).

Further study showed that SIB (Type 1) symptoms were not seen as a separate cluster. SIB (Type 2) was noted to be shared by Cluster I and Cluster II. SIB (Type 3) and SIB (Type 4) corresponded to Cluster III and Cluster I respectively (Table 10). This was further explored with discriminant analysis.

Table 9: Ability of SIB symptom in differentiating clusters

SIBSCL	Cluster 1 %	Cluster 2 %	Cluster 3 %	Cluster 4 %	Statistics χ^2 , df	P value
Mouthing	100	0	0	0	70, 3	0.001
Biting	0	0	100	0	61.96, 3	0.001
Banging	0	100	0	0	7.31, 3	0.06
Poking	0	100	0	0	0.94, 3	0.8
Picking	0	0	0	100	41.73, 3	0.001
Eye	0	100	0	0	1.43, 3	0.6
Mouth	66.7	33.3	0	0	45.54, 3	0.001
Head	0	0	100	0	17.82, 3	0.001
Extremities	0	0	100	0	61.97, 3	0.001
Body side	0	0	0	100	50.86, 3	0.001
Scarring	0	0	0	100	7.86, 3	0.04
Callus formation	25	56.3	18.8	0	16.61, 3	0.001
SIB >100	0	0	100	0	12.35, 3	0.006
Agitation if SIB Stopped	0	0	0	100	7.86, 3	0.04

Table 10: Comparison of literature based algorithm and cluster based algorithm symptomatology.

<i>Theory based algorithm</i> (N=70)		<i>Cluster based algorithm</i> (N=70)	
Type 1 (N=4)	Auto-amputation, bony injuries, LOC, extensive laceration (>3×3 cm), face, lips, extremities (fingers, toes)	Cluster I (N=4)	Painless, perioral injuries with callous formation
Type 2 (N=17)	Repeated rubbing, side of face, body, mouthing- wetting, callous formation.	Cluster II (N=48)	Banging, poking of head and eyes resulting in significant pain
Type 3 (N=46)	Head-banging, slapping, Biting + high rate	Cluster III (N=10)	Biting, extremities, head, high-rate behaviour
Type 4 (N=3)	Head-banging, slapping, biting + symptoms of agitation when SIB is interrupted.	Cluster IV (N=8)	Picking, body side, agitation if interrupted

VIII. Discriminating ability and ranking of SIBCL items

Discriminant analysis was used to determine SIB symptoms that can distinguish children by group membership and ranked them. Therefore, we analysed the discriminant function of each SIBCL symptoms using the Wilks' Lambda (Table 11).

Table 11: Discriminant values of all SIB symptoms

SIBCL symptom	Wilks' λ	Sig.	SIBCL symptom	Wilks' λ	Sig.
Mouthing	.(a)		Head	.74	.001
Biting	.11	.001	Extremity	.11	.001
Banging	.89	.06	Body side	.27	.001
Poking	.98	.8	Scarring	.88	.04
Picking	.40	.001	Callus formation	.76	.001
Eye	.97	.7	SIB>100/hr	.82	.005
Mouth	.34	.001	Agitation on interruption	.88	.04

.(a)= Cannot be computed because this variable is constant in each group.

The Wilks' Lamda reflected the finding noted with the Chi-square tests (Table 9) to examine if all selected clustering variables differentiated groups where banging, poking and eye as the site of injury did not have significant discriminating property as individual symptoms.

We further ranked the SIBCL symptoms in contributing to the discriminating power within each cluster using the standardized coefficients after the variables were standardized with a mean of 0 and variance of 1. It is suggested that the value of the standardized coefficient can be interpreted as the relative importance of the particular variable (Table 12).

Table 12: Correlation of variables with discriminant function (structure Matrix) and centroids.

	Function 1 59.6% ^a	Function 2 34.6% ^a	Function 3 5.8% ^a
Biting	.641 ^b	.178	.044
Extremity	.641 ^b	.178	.044
SIB>100	.107 ^b	.030	.007
Body side	-.134	.473 ^b	.040
Scarring	-.107	.378 ^b	.032
Picking	-.100	.352 ^b	.030
Agitation on interruption	-.029	.103 ^b	.009
Mouth	-.042	-.096	.994 ^b
Callus formation	-.033	-.041	.379 ^b
Head	.009	.021	-.216 ^b
Banging	.005	.012	-.126 ^b
Eye	.002	.005	-.054 ^b
Poking	.002	.004	-.043 ^b
	Centroids ^c		
Cluster I	-10.831	.415	.018
Cluster II	3.324	.118	.000
Cluster III	-1.457	-6.424	.279
Cluster IV	-6.120	-3.040	-.276

^a = Explained variance.

^b = Variables that best represent the function.

^c = Canonical discriminant functions evaluated at group means

Analyses revealed that all three discriminant functions reliably differentiated groups (Function 1: $\lambda = 0.002$, χ^2 (df,18)= 402.02, $P = .000$; Function 2: $\lambda = 0.03$, χ^2 (df,10) = 220.68, $P = .000$; Function 3: $\lambda = .36$, χ^2 (df,4) = 64.80, $P = .000$).

IX. Diagnostic accuracy of the cluster based algorithm

Next, stepwise discriminant function analyses were conducted to determine the extent to which the SIBCL symptoms (independent variables) could predict SIB clusters among children with atypical development. We used the leave-one-out classification procedure to

determine how well the classification procedure would predict in a new sample (cross-validation).

Table 13: Discriminant analysis results by SIB symptoms for Cluster-based algorithm.^{a,b}

	SIB clusters	Predicted Group Membership				Total
		1	2	3	4	
Original ^a	1	4(100%)	0	0	0	4(100%)
	2	2(4.2%)	46(95.8%)	0	0	48(100%)
	3	0	0	10(100%)	0	10(100%)
	4	0	19(12.5%)	0	7(87.5%)	8(100%)
Cross-validated ^b	1	4(100%)	0	0	0	4(100%)
	2	2(4.2%)	46(95.8%)	0	0	48(100%)
	3	1(10%)	0	9(90%)	0	10(100%)
	4	2(25%)	0	0	6(75%)	8(100%)

^a 95.7% of original grouped cases correctly classified.

^b 92.9% of cross-validated grouped cases correctly classified.

On average, the discriminant function was able to predict more than 96% of cases correctly. The best performance was with respect to the Cluster III and Cluster I where the prediction was 100% accurate. Similarly, the function was able to predict the Cluster II SIB symptoms correctly to about 96%. Even among the Cluster IV SIB symptoms, the correct classification was to the extent of 86% (Table 13).

In the re-sampled data also the discriminant function was able to predict more than 93% of cases correctly and similar pattern of accurate classification was noted among the subgroups also (Table 13).

X. Model fit for the discriminant model of diagnostic accuracy of the algorithm

Finally, we assessed the goodness of the discriminant model. We used the Wilk's Lambda to assess this quality of the discriminant model. The significance level of the discriminant functions is determined by the value of Wilk's Lambda. In this case the value of Wilk's

Lambda was 0.002 to 0.36 with a significance level of 0.001 (Table 14). This implies that the mean values of the four groups (SIB clusters) are significantly different from each other and the discriminant model fit was good.

Table 14: Discriminant model fit describing the 4 cluster model

Test of Function(s)	Wilks' λ	Chi-square	df	Sig.
1 through 3	.002	409.02	18	.000
2 through 3	.032	220.68	10	.000
3	.363	64.80	4	.000

Table 15: The diagnostic accuracy details for each SIB subgroup against the theoretical model.

	Sensitivity (95% CI)	Specificity (95% CI)
Repetitive (SIB type 2) vs. Painless SIB (Cluster I).	0.23 (0.1to 0.23)	1 (0.96 to 1)
Self-mutilatory (SIB type 1) vs. Painful-violent SIB (Cluster II).	0.75 (0.31to0.95)	0.31 (0.29to0.33)
High-rate (SIB type 3) vs. High-rate (Cluster III).	0.13 (0.07to 0.17)	0.83 (0.72to0.92)
Agitation if SIB interrupted (SIB type 4) vs. Agitation if SIB interrupted (Cluster III).	0.33 (0.06to0.78)	0.89 (0.88 to 91)

The sensitivity and specificity of the algorithm for each of its subgroup classification was done with contingency tables and details are mentioned in Table 15.

Discussion

CHAPTER VI

DISCUSSION

We developed a new Self-Injurious Behaviour (SIB) typology to classify SIB among children with atypical development. This is the first time a cluster-analysis based clinical classification has been completed and a classificatory algorithm attempted. The newly developed SIB algorithms were comparable with previously published and widely used literature based algorithm for classifying children with SIB. This algorithm will enable clinicians to classify SIB based on the strong clinical evidence seen in children with atypical development.

The patient flow as described in the figure 2 provided 83 participants with SIB and equal number of children or adolescents without SIB matched for gender and IQ as controls. The control population was used for the analysis of factor structure of the SIB symptom validation and item reduction for the SIBC. The study population was all children or adolescents as required in the selection criteria with an age range of 9 months and 18 years. The all had confirmed diagnosis of mental retardation with an IQ range of 4 to 68, and thus had atypical development. Children in the SIB group were significantly younger chronologically than those children without SIB. Children with SIB also had significantly less adaptive skills and more psychological comorbidities than the no SIB group. These factors different between groups may be risk factors for SIB and further research work is required to establish them as predictive factors. However, as the aim of the study is not to

elicit the risk factors for SIB, the task was not undertaken. None of these factors significantly differed between the different literature based SIB subgroups suggesting that the different forms of SIB may not have any relationship to age, adaptive skills or psychological comorbidities. This hypotheses also needs further testing.

Prevalence of SIB based on the literature based algorithm

The total prevalence of SIB in the study population was 9.94% (83/835). The SIB type I that includes autoamputation, bony injuries, injury with lose of consciousness, extensive laceration ($>3 \times 3$ cm), face (lips), extremities (fingers, toes), scarring was noted among 4.82% (4/83) of children with SIB. SIB type II that includes repeated rubbing, side of face, body, mouthing- wetting, and callous formation was seen in 20.48% (17/83) of our study sample. SIB type III that is characterized with head-banging, slapping, biting and high rate behaviour was documented in 55.42% (46/83), and finally SIB type IV with a symptom profile of head-banging, slapping, biting and symptoms of agitation when SIB is interrupted was seen in another 3.61% (3/83) of the study sample. SIB- mixed type was noted in 12.66 (13/83) of the children.

Validation of SIB construct and reduction of SIB items

The second part of this research work focused on the identification of the most significant SIB symptoms that will identify the different pattern of SIB existing in the study sample. Out of the 24 SIB symptoms under 6 dimensions, three symptoms namely auto-amputation, bony injury and injury with lose of consciousness was not seen in any of the children included in the study and thus were dropped from the list of SIB symptoms. Thus

21 symptoms were further analyzed and it was noted that the items scarring and extensive laceration as well as mouthing and wetting were identical in their ability to pick-up symptoms and were clubbed in to 2 symptoms instead of the original four symptoms. Thus only 19 SIB symptoms were found to be useful in profiling the SIB in our study population.

When we explored the internal consistency of the 19 items the Chronbach's alpha was low for all the dimensions. This explained to us that the SIB items and dimension were not homogenous in nature constructually. Therefore, to further explore the construct of the SIB symptoms and to further reduce the SIB symptoms we did an exploratory factor analysis and it was *a priori* decided to include only those SIB symptoms with a loading score of 0.4. Although factor analyses are typically based upon non-dichotomous variables, the use of dichotomous variables is justified in exploratory approaches (Alsobrook & Pauls, 2002). The factor loadings rotated orthogonally by normal Varimax method (Kaiser, 1958) to yield new factor loadings with simple structure has been used for medical interpretation of the factors.

The principal component analysis showed that the symptoms of rubbing, slapping, pulling, face, laceration/scarring, did not load on to any factor and thus were further dropped from the SIB list. None of the symptom cross-loaded. Thus, finally the 14 items that loaded to any one of the factors formed our Self-injurious Behaviour Checklist (SIBSC). These symptoms were biting as mode of injuring, extremities being injured, SIB rate of > 100/hour making the factor of (*Factor: High rate limb biting*); mouthing, banging as mode of injuring, buccal cavity and mouth, head being injured, callous formation (*Factor: Head banging and mouthing with callosity*); picking as mode of injuring, sides of body being

injured, agitation if SIB is interrupted (*Torso picking with agitation when SIB is stopped*); poking as mode of injuring and eye being injured (*Eye poking*). This checklist symptoms (N=14) were further used in the cluster and discriminant analysis.

Cluster development and identification

The present study identified four distinct subgroups of children with SIB. We identified the number of clusters of children in our sample with cluster analysis. To characterise our sample in terms of SIB symptoms identified with the factor analysis, we again used cluster analysis.

After the predictor variables were tested and found to meet the basic assumptions for linear modelling, the analysis was continued. We used an agglomerative hierarchical clustering procedure that produces clusters by identifying cluster centres based on similar characteristics demonstrated in the analysis by the participants. This is a multivariate approach to classifying as opposed to univariate classification, in which the participants place themselves into one category or another (Norusis, 1988). In other words, instead of using a single item or scale to classify a child, numerous SIB items, in the form of several symptoms (predictor variables) were used to identify and classify the children.

Before the cluster analysis was conducted, all values were converted to Z scores or standard values. This was done to avoid the inappropriate influence of variables with large scale scores as compared to variables with small scale scores. For example, a checklist subscale with a more number of symptoms and a subscale less number of items will affect the cluster analysis differently. The larger value of the first scale will be calculated as having a greater value than the same percentage score of the second scale. In other words,

unless Z scores are used, a person getting a score of 25 on the first scale and a score of 5 on the second scale will not be calculated as getting 50% of the total possible scores on each scale. This was needed as some of the subscales had more number of items and some less in the SIBSC. Ward technique of hierarchical cluster analysis (Ward 1963) was used because it was suitable for cluster analysis based upon the relationships between the items and was superior in yielding easier medical interpretation of isolated clusters. Also, because the interest of this research is to measure the magnitude of the difference between clusters, a distance measure namely the squared Euclidean distances to derive cluster centres were deemed appropriate.

We examined clusters at various levels to give the most useful grouping. Percentage of change in the agglomeration coefficient (i.e., within clusters sums of squares) from stage to stage was examined to determine the most appropriate number of clusters. Small incremental change suggests that relatively homogeneous clusters were combined in the previous step, whereas larger change suggests that relatively heterogeneous clusters were combined (Hair et al, 1998). By this method we determined that a 4-cluster solution was the ideal one as it has the highest percentage agglomeration coefficient change. When five clusters were reduced to four clusters the change in the coefficient was 12.9% with the difference in coefficient of 4.46%. Any value more than 3% difference between coefficients in consecutive agglomeration may be considered significant. An 8-cluster solution may also be considered good as when the 9 clusters were reduced to 8 clusters the difference in the agglomeration coefficient was 3.3%.

As the difference in coefficient change was larger with 4-clusters than with 8-clusters and as the 4-cluster solution was supportive of the theory driven algorithm, we preferred to continue with the 4-cluster solution.

Characterisation of cluster profile:

Children in Cluster I exhibited greater concern for Factor 2 (Head banging and mouthing with callosity) with mostly painless SIBs, than for Factor 1 (High rate limb biting), Factor 3 (Torso picking with agitation when SIB is stopped) and Factor 4 (Eye poking) than for the other three clusters. Therefore, Cluster I was titled *Painless Self-injurious behaviours*. This corresponded to Type 2 SIB in literature.

Cluster II rated fairly across multiple factors and multiple painful SIBs and was named *Violent-painful Self-injurious behaviours*. This corresponds to the Type 1 SIB in literature.

Cluster III rated Factor 1 as important and thus was called *High-rate self injurious behaviour*. This corresponded to Type 3 SIB in literature. Cluster IV grouped under it children with Factor 3 symptomatology and hence was called *SIB with onset of agitation when SIB is prevented*. This corresponded to Type 4 SIB in literature.

In the cluster assignment analysis it was noted that although there were differences in the cluster assignment when compared with the literature based SIB groups, but where not totally. This helps confirm that the groups identified by the cluster analysis procedure are similar to the criterion provided by theoretical model. This grouping into clusters is not totally clear cut but it does accord with clinical experience. Clusters such as these may provide a basis for the study of the grouping of SIB and evaluation of treatment by drugs or psychological methods.

Validation and diagnostic accuracy of the new algorithm

The discriminant analysis we carried out to validate the cluster-based algorithm and cluster analysis we used to develop clusters may sound similar, in that they both classify cases into categories. However, the difference is the discriminant analysis requires one to know group membership. Cluster analysis does not need a grouping variable; it creates one. The product of cluster analysis is the identity of homogeneous cases that it assigns to groups or clusters. After completing the cluster analysis, the cluster groups become the classifying variable in a discriminant analysis. With this classification variable, the discriminant analysis derives a rule for identifying children with similar SIB. Furthermore, discriminant analysis produces discriminant functions of the variables that separate the groups. The variables and their coefficients in these discriminant functions describe the different characteristics between the groups or in other words it determines which variables contributed to the distinctions of the clusters.

Among the SIB symptoms, banging, poking and eye as the site of injury did not have significant discriminating property as individual symptoms. However, biting and extremity (Function 1), body, scarring and picking (Function 2) and mouth, callus formation, head banging, eye and poking (Function 3) discriminated the groups.

Analyses revealed that all three discriminant functions (Function 1: $\lambda = 0.002$, χ^2 (df,18)= 402.02, $P = .000$; Function 2: $\lambda = 0.03$, χ^2 (df,10) = 220.68, $P = .000$; Function 3: $\lambda = .36$, χ^2 (df,4) = 64.80, $P = .000$) reliably differentiated groups. Functions accounted for 59.6%, 34.6%, and 5.8%, respectively, of the between-group variability. Based on the discriminant functions, cluster membership was predicted for each participant. Results revealed a high hit rate; 96% of children were correctly classified with original sample and 93% correctly

classified with resampled sample. Except for the subgroups of SIB, Painful-violent SIB (Cluster II) all the other subgroups had a high specificity as in Table 15.

Also the model fit as suggested in Table 14 indicated a good model fit. The apparent robustness of the distinction between the 4 different SIB subgroups across our samples suggests that, despite their similarities, these subtypes characterised by pain, violence, high rate of injury and agitation when SIB is interrupted are possibly biologically different.

Clinical importance of this study

One of the potential uses of the cluster analysis in this study is that the findings suggest that different treatment approaches may be beneficial for the different groups of SIB. One can hypothesise that the children with Violent-painful SIB (Cluster II) may benefit most from an opioid blocker like naltraxone. Children with repetitive Painless SIB (Cluster I) may respond better to dopamine blockers where as those with high rate behaviour (Cluster III) may respond to Selective serotonin reuptake inhibitors. A child in the cluster with agitation when SIB is stopped (Cluster IV) are most likely to benefit from noradrenergic medication like lithium or β -blocker. Such hypotheses merit testing in controlled studies.

Limitations

Several limitations of the present study are notable.

First, this study included only children with atypical development presenting to a tertiary care facility and the sample size was relatively small. As such, it is important to reiterate the exploratory nature of this study and lack of generalisability. The size of the sample, although adequate for an exploratory study (Hair et al, 1998), needs to be increased so that there can be more depth of analysis.

Second, which criteria are the best for selecting the number of clusters in a data set is a matter of ongoing debate. The use of different criteria for determining the cluster solution might have resulted in the identification of a different number of groups of children with SIB. Although this is always a potential criticism of cluster analytic techniques, converging evidence from the analysis of agglomeration coefficients analysis and the dendrogram suggested that the four-cluster solution identified in the present study was appropriate.

Third, as is the case with all cluster analyses, the use of different variables in the analysis might have resulted in a different cluster solution. However, the general similarity of these results to the theoretical model and the results of the discriminant function analysis suggesting stability of classification across sub-samples all provide evidence for the reliability of the present results.

Future directions

The next stage of research should include a new sample whose data could be analyzed using confirmatory cluster analysis to validate the clusters. Also, a new and larger sample would allow researchers to determine if there are SIB symptom differences between the clusters that are related to the importance the different groups placed on the various medication treatments.

Conclusion

CHAPTER VII

SUMMARY AND CONCLUSION

The study was conducted to derive a new typology for use in algorithmic manner for Self-Injurious Behaviour (SIB) among children with atypical development and validating it further.

The prevalence of all types of SIB was 9.94%.

The 24 SIB symptoms described in the literature were reduced to 14 items under 4-factor structures.

The 13 symptoms generated 4 clusters of children with SIB symptoms specific to each cluster named as Painless SIB cluster, Violent-Painful SIB cluster, High-rate SIB cluster and Agitation when SIB was interrupted.

All the 13 SIB symptoms except the symptoms of eye, banging and poking were able to discriminate between clusters. However, when combined with other SIB symptoms that characterized their cluster they were important in discriminating one cluster from the other. Good fit for the discriminate model and high correct classification rate among two samples was demonstrated.

Our results indicate a comprehensive typology of Self Injurious Behaviours that exists among children with atypical development. It supports the importance of lack of pain with callous formation, violence and pain as the main symptom of SIB, high rate of injury and agitation when SIB is interrupted as underlying main symptoms in these subgroups of SIBs. It needs to be tested if they could be assigned to different medication trials like

dopamine blocker, opioid blocker, serotonin modulators and noradrenergic modulators respectively.

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Appendices

SOCIODEMOGRAPHIC DETAILS

NAME OF THE PATIENT

AGE

GENDER

HOSPITAL NUMBER

NAME OF THR PARENT

SELF INJURIOUS BEHAVIOR : YES /NO

DESCRIPTION OF THE
SELF INJURIOUS BEHAVIOR :

TOPOGRAPHY :

DURATION :

FREQUENCY :

SEQUELAE :

INTELLIGENCE QUOTIENT
(IQ SCORE) :

DISABILITY LEVEL :

VINELANDS SOCIAL MATURITY SCALE
(VSMS SCORE) :

MEDICAL COMORBIDITY :

PSYCHOLOGICAL COMORBIDITY :

:

SELF-INJURIOUS BEHAVIOUR CHEKLIST

SIB SYMPTOMS

DOES THE CHILD HAVE SIB CAUSING AUTO AMPUTATION ?

DOES THE CHILD HAVE SIB RESULTING IN BONY INJURIES ?

IS THERE LOSS OF CONSCIOUSNESS ASSOCIATED WITH THE SIB?

DOES THE SIB RESULT IN EXTENSIVE LACERATION?

DOES THE SIB INVOLVE THE FACE OR EXTREMITIES?

DOES SIB RESULT IN SCARRING?

IS THERE REPEATED RUBBING ON THE SIDE OF THE FACE, BODY?

IS THERE REPEATED MOUTHING AND WETTING?

DOES SIB RESULT IN CALLOUS FORMATION?

IS THERE ANY HEAD BANGING, SLAPPING, OR BITING SYMPTOMS?

ARE THERE ASSOCIATED SYMPTOMS OF AGITATION LIKE SCREAMING,
PACING, SWEATING, HYPERVENTILATION AND TACHYCARDIA?

IS THE SIB RATE GREATER THAN 100/HOUR?

IS THERE AGITATION WHEN SIB IS INTERRUPTED?

INFORMED CONSENT FORM

Title of study:

Diagnostic accuracy of a classificatory algorithm for self injurious behavior in children and adolescents with developmental disabilities.

Institution:

Christian Medical College & Hospital,
Vellore.

Hospital No:

Nature and purpose of the study:

You and your children are taking part in a study to assess the nature of self injurious behavior, its topography, and frequency, and to validate a classificatory algorithm for self injurious behavior.

Explanation of procedure to be followed:

A CMCH doctor from the department of psychiatry will conduct this study. You will be asked questions pertaining to the child's self injurious behavior, rate, frequency, and topography. The child's social age, IQ, medical and psychological co morbidity will also be assessed. SIB will be classified according to the algorithm and the same will be validated.

Expected duration of involvement:

Duration of the assessment will be about three hours.

Article I. Possible benefits of the study:

You will not be charged for this assessment. The information we obtain may help in providing better understanding of the type of self injurious behavior, the putative neurotransmitter involved and hence may help in the treatment of SIB. Others may also benefit from the overall conclusions at the end of the study.

Article II. Confidentiality

The records and all details obtained in this study will remain strictly confidential at all times, but will need to be available to the doctor conducting the study. Your identity will not otherwise be revealed. Your personal data will be collected and processed only for the research purposes in connection with the study. You will not be referred to by name or identified in any report or publication.

Section 2.01 Right to withdraw from the study

You are free to leave the study at any time. Your decision to not to participate in this study will not affect our future medical care.

Article III. Consent

I/We have read/.....had read out to us, the above information before signing this consent form.

Signature of the parent of the patient

Signature of the person obtaining consent.